‘HANDS OFF OUR STORIES’.

EXPLORING THE LEGACIES OF PATIENT NARRATIVES ‘CAPTURED’ FOR QUALITY IMPROVEMENT

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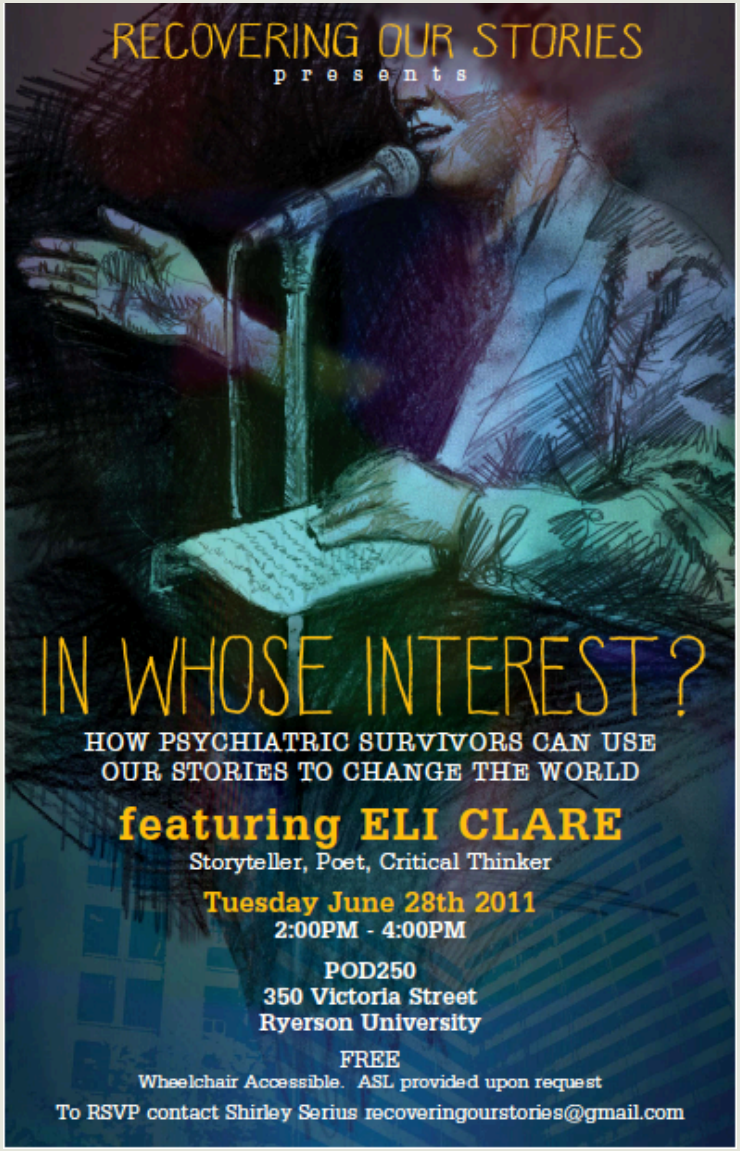
‘Hands off our stories’, Canada 2011

“ … describes a community event organized in response to the appropriation and overreliance on the psychiatric patient ‘personal story.’ The sharing of experiences through stories by individuals who self-identify as having “lived experience” has been central to the history of organizing for change in and outside of the psychiatric system. However, in the last decade, personal stories have increasingly been used by the psychiatric system to bolster research, education, and fundraising interests. We explore how personal stories from consumer/survivors have been harnessed by mental health organizations to further their interests and in so doing have shifted these narrations from ‘agents of change’ towards one of ‘disability tourism’ or ‘patient porn.’ ”

Costa L, Voronka J, Landry D et al. (2012). ‘Recovering our stories: a small act of resistance’. Studies in Social Justice, 6(1): 85-101

Stories as commodities



"We all have stories. Many of our stories are deeply personal. Some of our stories are painful, traumatic, hilarious, heroic, bold, banal. Our stories connect us - they reflect who we are and how we relate to one another. Stories are extremely powerful and have the potential to bring us together, to shed light on the injustice committed against us and they lead us to understand that not one of us is alone in this world.

Becky McFarlane, Recovering Our Stories event, June 2011

"But our stories are also a commodity - they help others sell their products, their programs, their services - and sometimes they mine our stories for the details that serve their interests best - and in doing so present us as less than whole."

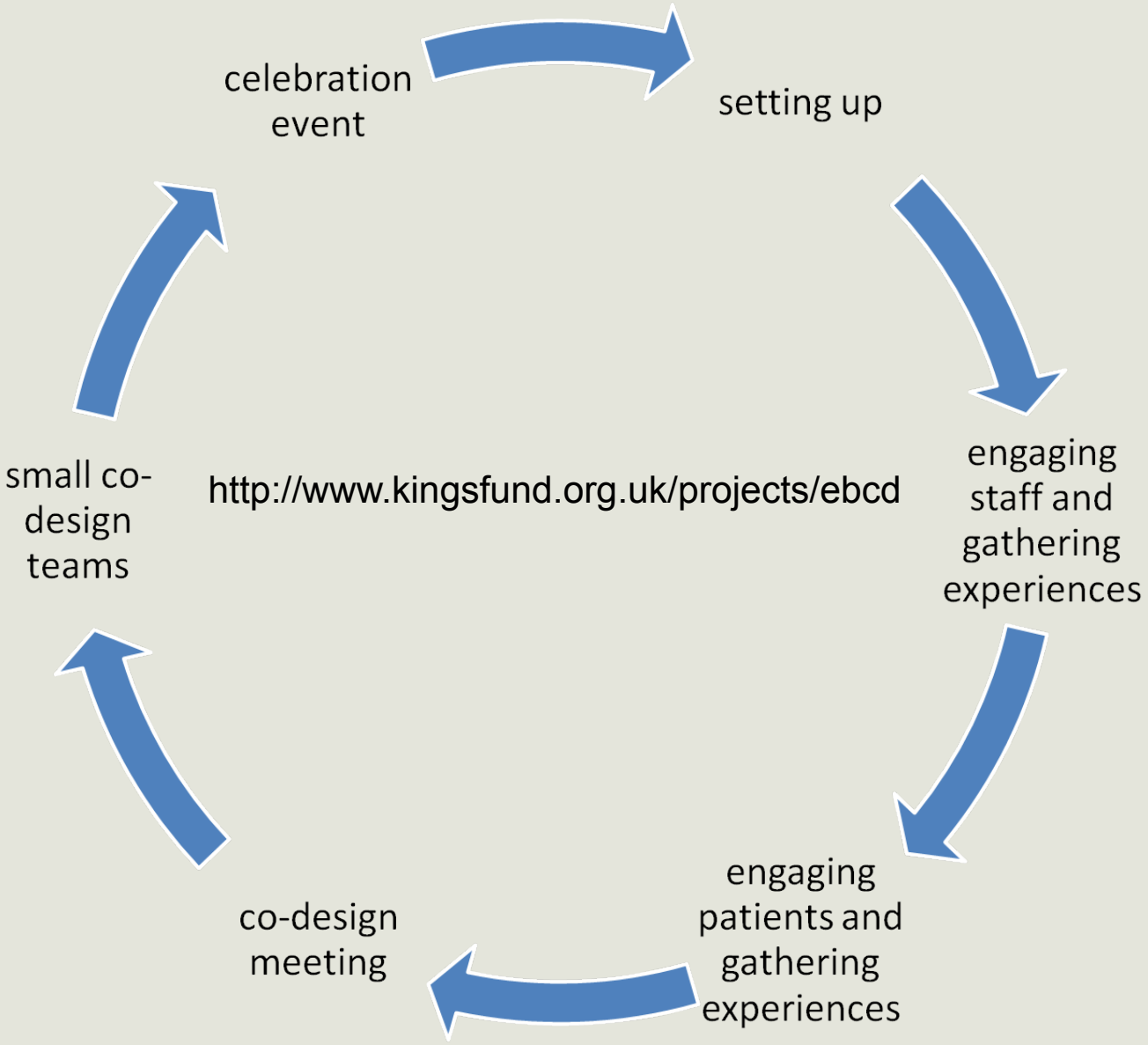
A patient story, 2005

Aim

- to examine the ways that - over time - filmed patient stories acquired and re-acquired meaning as sources of knowledge for clinical and quality improvement staff

- part of a wider study exploring the two-year sustainability of quality improvements arising from using Experience-based Co-design (EBCD) in an Integrated Cancer Centre

A participatory action research approach that combines: a user-centred orientation (Experience-based) and a collaborative change process (Co-design)


celebration event
setting up
engaging staff and gathering experiences
engaging patients and gathering experiences
co-design meeting
small co-design teams
http://www.kingsfund.org.uk/projects/ebcd

Stories and Experience-based Co-design

Extract from patient film – a touchpoint

Co-design


'HUB'
Patients referred on other hospitals
Patients who are referred from consultant clinic
Some people managed in community
48 HOURS / 2 NIGHTS


08.10.2011 14:31

Setting – Integrated Cancer Centre, 2009-10

- Knowledge & skills transfer:
  - trained 2 in-house QI specialists
  - mentored through the process
- Fieldwork involved:
  - 36 filmed narrative patient interviews
  - 219 h of ethnographic observation
  - 63 staff interviews
  - a facilitated EBCD process over 12-month period
- 7 co-design groups
- 56 quality improvements

- Two years later, traced quality improvements and studied sustainability
- 19-22 months after initial implementation, 66% of improvements sustained:
- 'Quick fix' solutions: 28 (with 24 sustained)
- 'Process redesign' solutions: 9 (5)
- Cross service or interdisciplinary solutions: 14 (8)
- Organisational level solutions: 5 (2)
- Crucial role of facilitators in determining staff experiences of the EBCD approach

Tsianakas, V., Robert, G., Maben, J., et al. (2012). 'Implementing patient centred cancer care: using experience-based co-design to improve patient experience in breast and lung cancer services'. Journal of Supportive Care in Cancer, published online DOI 10.1007/s00520-012-1470-3

The 'narrative contract' ... over time

- shared agreement between teller and audience of what is possible (meaningful, recognizable and believable) which regulates "the terms of the narrative or story" (Gabriel, 2004b:172)
- without a narrative contract a story might be challenged on two possible different grounds: 'So What?' (fails to carry shared meaning), and 'Did It Really? (fails to carry verisimilitude)
- 'Who are you to speak with authority?'
- a persuasive narrative relies on a degree of shared moral orientation between tellers and listeners to be recognised as a source of knowledge
- examine professionals' initial response to, and later interpretations of, the patient film as a legitimate or questionable source of knowledge for their clinical and organisational work

Gabriel Y (ed.). (2004). 'The narrative veil: Truth and untruths in storytelling'. pp. 17-31 in *Myths, Stories and Organizations: Premodern narratives for our times*. Oxford: Oxford University Press;
Gabriel Y . (2004b) 'The voice of experience and the voice of the expert – can they speak to each other?'. pp 168-185 in *Narrative Research in Health and Illness*. Eds Hurwitz B, Greenhalgh T and Skultans V. Oxford: Blackwell Publishing

Methods

Interviewees	Number
Clinical/support staff	15
Patients	4
QI facilitators	9

All interviewees involved in patient film screenings and subsequent co-design work

Interviews conducted between 21-31 months after film first screened

Thematic analysis

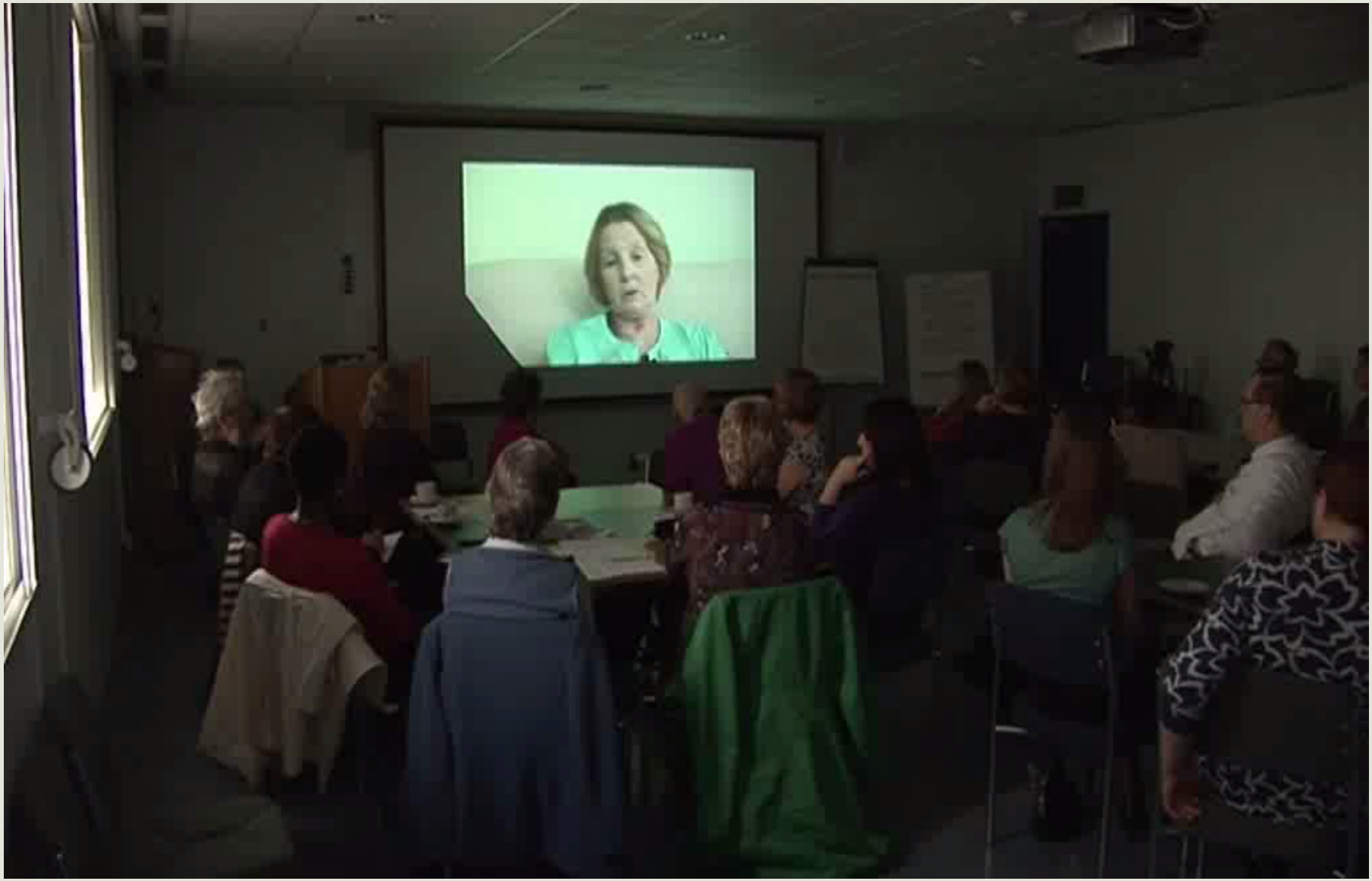
Findings

- Film screening and initial interpretations

- Re-interpretations two years later:
  - Ongoing sources of learning
  - Dubious representations of patient experience
  - Auditable evidence

- What shaped those reinterpretations:
  - Social distance
  - Differential outcomes of QI work
  - Different organisational agendas

Film screening



Film screenings and initial interpretations

"I think the film was the catalyst to solving the problems … This was the thing that absolutely broke down the wall and made people really see clearly that it had to stop and that people' s attitudes had to change … there is something very powerful about film … it engages everybody, its' not just reading things or listening to things … The visual side of it I think is very important" (Senior nurse)

- at this initial screening, our informants recalled, audiences were united in agreement over the veracity and significance of the patient film in informing their forthcoming co-design work

- at least at this time, the film effectively brokered a narrative contract that directed a shared ethical endeavour of QI

Reinterpretations two years later

- the film had acquired more contested meanings and valuations

  – sometimes the film continued to be valued as a heuristic tool to stimulate reflection and build consensus for change
  – at other times the film had acquired more diffuse meanings, either as a (largely unsuccessful) representation of biographical knowledge or as a (often questionable) general representation of patient experience
  – the film sometimes became readily incorporated into the dominant epistemic of evidence established by audit and accounting

Patient Films as On-going Sources of Critical Reflection

"They showed footage of these patients and they were saying 'Oh yes, I went to a lung cancer clinic and the doctor told me my cancer and he didn't even look at me, he was looking at the screen' … so there was a particular, for instance, focus on the moment they were told they had cancer, which was interesting and obviously that's very important to them in the whole pathway, that particular moment was really critical … so that's something that I took away as being important … it does make me pause for a moment at that point and think and look the patient in the eye and just try and measure it and judge it a bit, so I think that was probably quite helpful … after ten years of doing this, to just pause and think, 'Okay, this bit really matters now' and focusing on that." (consultant)

'I don't do patient centred care'

Patient Films as On-going Sources of Critical Reflection

"They had an audit day and so we had everybody out of day surgery [and] in the room, so we showed the film … and actually people cried … Some of them were visibly shocked by what the patients said … and I thought at the time, God… we already knew [the film] was powerful, but I thought to see [staff] like that… I think if you're a theatre person you don't see the everyday emotion …" (nurse consultant)

"When you see the video and you can see the emotion and you can see what's happened … it's very hard to argue with an experience. You can't argue with that; it's their experience. If it's just written down it's easy to dismiss, it's easy to dismiss opinions. When it's in your face and you see it, it has a much deeper psychological impact." (QI facilitator)

… but also …

Patient Films as Dubious Representations of Patient Experience

"It all comes down to who holds the budget … that's the bottom line … all these things like private time and ferns in the corridor … it's not realistic … it's all a big consumption of medical time if you stick a doctor and a nurse and a relative and a few more patients in a room and just let them run free for an hour or so and that just consumes a huge amount of time … It's not going to meet the needs of the greatest numbers." (consultant)

"Of course, from a scientific point of view it was a very small number of patients … almost by definition they are not going to be representative because they're alive and most are dead within a year … they are a selected group … but I know that the patients were interviewed. I'm sure they were because they were videoed." (service improvement lead)

Patient Films as Dubious Representations of Patient Experience

- the immediate and vitalising effects of the film had tended to dissolve and questions were now raised about the relevance or veracity of the issues portrayed

- particularly true amongst clinicians and project staff who had not achieved what they hoped from the co-design work

- at the same time, however, staff continued to express their support for the EBCD and patient film work because it countered the “dumbing effects of questionnaires” and the “blindness to patients [caused by] heat maps and endless data collection”

Films as 'Closed' Items of Evidence of Quality Improvement

"The DVD is a huge resource for us because this is seen as independent work … which is good when you are dealing with patient experience… because patient experience is everywhere now … there's a lot of focus in the organisation on this … there's more and more of it." (QI facilitator)

"Here senior managers told of the benefits of their patient film work and we eagerly accepted their invitation to 'see the patient film'. At this visit the service manager pulled a folder labelled "Peer Review" from her bulging office shelves and showed 'the film' - pristine in its study plastic cover. "This", she explained, pointing at the DVD case "this is the film". She described the value of this item as vital in demonstrating that we do patient experience." (extract from fieldnotes)

What shapes those reinterpretations

Social distance

Differential outcomes of QI work

Different organisational agendas

Discussion – the ‘narrative contract’

- shifted the terms of the narrative contract as some staff, as well as patients, began to question the veracity of the films: to ask the ‘Did It Really?’ question

- the value of the films were also sometimes re-inscribed in different terms: the narrative contract was breached as staff began to ask “So What? (What Is This To Me?)”

- ‘Who are you to speak with authority?’

Humanising healthcare

Forms of humanization	Forms of dehumanization
insiderness	objectivication
agency	passivity
uniqueness	homogenization
togetherness	isolation
sense-making	loss of meaning
personal journey	loss of personal journey
sense of place	dislocation
embodiement	reductionist body

Todres L, Galvin T and Holloway I. (2009) 'The humanisation of health care: a value framework for qualitative research. *Int J of Qualitative Studies on Health and Wellbeing*, 4: 68-77

Summary

- voice of experience and voice of the expert: a dialogue
  - immediate reception of the film as critical medium that skillfully brokered a 'patient perspective'
  - when staff able to act on the expressed needs of patients, the film retained authority as testimony and against [illegible]
  - 2 years after viewing, all informants initially remembered the film even though many contested their veracity or significance to QI
- something inherently fragile, or fluid, about patient stories as a form of valid knowledge in late modern organizational systems
  - the film stood as a popular but questionable counterpoint to the dominant values of calculative and reductive audit practice with their rhetoric of efficiency and scarcity
  - successful brokerage of patient stories, through co-design, sustains legacy as an alternative form of knowledge

'The road to hell is paved with good intentions'

Implications

- longevity of filmed patient stories to operate as a stand-alone source of ‘collective sense-making’ for QI work?

- as part of change process (providing ‘time, patience and trust’) films play important role in reducing social distance, reassembling the social, (re)connecting

- embed ‘designerly’ thinking in organisations (rather than experience data)

- start from QI system design features – humanising health care

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